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ABSTRACT

African American pastors are increasingly becoming involved in the care and understanding of those infected with HIV and AIDS. In this pilot project, lay leaders of a Methodist Church in Queens, New York participated in a facilitator training program for AIDS bereavement. A variety of theoretical perspectives that included bereavement theory; group work; cultural diversity and empowerment practice; community theory; and adult learning theory were drawn upon to develop the program for facilitator training. The emphasis on training lay leaders from the church community offers an additional resource for community agencies. A survey was conducted to discover how the lay leaders responded to a structured training program run by a minister, a professor, and a social worker. Analysis indicated that the training met most of the didactic and emotional needs. However, lay leaders suggested that churches and other community organizations need to build and sustain guidance and educational efforts to prevent AIDS. (Contains 6 tables and 19 references.) (JDM)

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AIDS Bereavement Support Group: A Qualitative Analysis of Training Transcripts

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Introduction

The popular press infers that African Americans have turned their backs on those suffering from AIDS (New York Times, 1999, 1998; Newsday, 1998). However, a survey by Moore and Conboy (1998) revealed that African American pastors are becoming increasingly more vocal in their appeal for compassion and understanding in the church community towards those who are infected and affected by HIV/AIDS. Not only were pastors cognizant of the ravenous nature of AIDS in African American communities, but they were also very insistent that the church join in the struggle against AIDS. Their concerns about the high number of African Americans infected (10 times higher than whites, New York Times, 1999); the complications associated with AIDS illness and grief; as well as the theological dilemmas posed by AIDS were all factors that motivated them to participate in the survey. The pastors identified books on bereavement and AIDS (71%), onsite bereavement counseling training (62%), and a workbook to self-train on AIDS bereavement (60%) as the kind of help they need in order to develop AIDS grief ministries (p.18). One minister requested a facilitator / trainer to meet immediately with a group of lay-leaders in his congregation in order to begin developing an AIDS grief ministry (Illness, Crisis & Loss, October 1999, pp. 390-401). The aim of this article is to summarize the program offered and to qualitatively analyze the interactions of lay-leaders during the training.

Lay Leadership Training: A Pilot Project

Lay-leaders of the Springfield Gardens United Methodist Church in South East Queens, New York were appointed by their senior pastor to serve as a pilot group in the development of a facilitator training program for AIDS bereavement. The church was interested in establishing an AIDS ministry and in creating a model that could be used by other churches to develop AIDS ministries. The Wurzweiler School of Social Work of Yeshiva University sponsored lay leadership training. A minister at the church who had also been a student at Wurzweiler and currently lives in the church community became a co-leader of the training group. Six church members were selected for training. There were three women: a nurse, a teacher in the church's nursery school program, and the mother of an adult son with AIDS and three men: an HIV/AIDS counselor, a seminarian, and an individual suffering with AIDS (Moore, 1999, p. 393).

Theoretical Foundation of Facilitator Training Group

A variety of theoretical perspectives that included bereavement theory, group-work, cultural diversity and empowerment practice, community theory, and adult learning theory were drawn upon and synthesized to develop the program for facilitator training. The final product presents a model of a community level intervention that is culturally sensitive and is designed to specifically address the need for AIDS grief services in African American churches. The emphasis on training lay leaders from the church congregation draws upon an alternative resource to community agencies. Lay-

leaders are often individuals with a strong sense of self worth whom the community identifies strongly with individually, yet they are part of a larger group of individuals who have been disenfranchised by the larger American society. Consequently, by training these individuals, the emphasis serves to empower them to become even better servants in their own communities. This is a particularly relevant issue for African Americans.

Facilitator training is based on principles of adult learning that values individual autonomy. It encourages participants to play an active role as they apply new concepts to their immediate practices (Strenick, et al., 1998, p. 102). Knowles (1980) has recommended group process as an important format for teaching adult learners since new knowledge and improved skills can be acquired through a process of mutual exchange and problem-solving activities. The role of the leader is to facilitate the group process and to provide technical assistance as the group works to achieve its goals. Leaders can also help group members establish valuable linkages with other outside service providers (Moore, 1999, p. 392).

Group Structure

Over a three-month period, six participants met bi-weekly for 5 hours per session. During the first session, ground rules were established and participants' learning needs were determined. Participants spoke freely about their faith in Jesus Christ and a desire to seek Christ's guidance in all aspects of their work together (Moore, 1999, p. 394).

All participants were active church members and agreed to a schedule of meetings that would include experiential exercises, didactic learning which included theoretical information about bereavement, the viewing of training videotapes about AIDS impact of families and communities, and tasks related to development of a church structure to support an AIDS ministry. (Participants also suggested that a 30-minute lunch break be included in the training and each contributed food).

Table I. Goals of Facilitator Training

1. Increase facilitators' understanding about the need for support.
2. Increase facilitators' awareness about their own feelings of grief, loss, and dying.
3. Increase facilitators' ability to listen without being judgmental and feeling "good or bad."
4. Increase facilitators' ability to tell the difference between normal and complicated bereavement.
5. Increase facilitators' knowledge about the similarities and differences between grief associated with the phases of chronic illness and the phases of bereavement.
6. Assist facilitators in developing an operations manual to guide development of a bereavement support group in the congregation and church community.

Table I summarizes the goals for training as identified by group leaders and facilitators during the contracting phase of working together. The following themes emerged: (1) What is a support group? (2) What is normal, complicated, and disenfranchised (AIDS) bereavement: (3) The stages of AIDS illness and related stresses for families. (4) Starting your own AIDS bereavement support group, and (5) Evaluation of training experience (Moore, 1999, p. 393).

In session one, participants were led in an experiential exercise in which they were able to "tune in" to the importance of active listening, effective communication,

and a non-judgmental stance when counseling people grieving AIDS losses. Session two involved a general overview of bereavement theory and focused specifically on the complexities associated with AIDS bereavement. Session three emphasized the parallels between AIDS as a chronic illness and the grief process. Chronic illness typically involved a period of mourning as individuals with a chronic illness and their loved ones learn how to cope with changes brought on by the illness. The need for African American communities to develop partnerships with other groups and service providers in order to cope with AIDS illness and AIDS deaths was also emphasized. Session four featured a tape focusing on church based health ministries. Participants worked independently with a workbook to think through the process of starting an AIDS bereavement group using the group facilitators as consultants. This process led to their need to continue working on their own for one session without the input of the facilitators. The final session, session five, was devoted to a review of the participants' draft of an operations manual for the AIDS ministry and providing feedback on the training experience.

The research questions asked are noted in Table II.

Table II

1. How do lay leaders respond to group bereavement training?
2. How do lay leaders respond to the dual-leadership of a minister and professor / practitioner of social work?
3. What are the major themes the lay leaders talked about in the training sessions?
4. Did the responses and major themes show congruence with the training material and themes?

Methodology and Sample

In order to discover how lay leaders respond to a structured training program run by a minister and professor and practitioner of social work, a qualitative research study (Ruckdeschel, Earnshaw and Firrek, 1994; Witkin, 1994; Tutty, Rothery & Grinnell, 1996, Padgett, 1998, and Miles & Huberman, 1994) was conducted. A content analysis of transcripts was done (Coleman & Unrau, 1996, 1997; and Berg, 1995) of the five group sessions held at a church and which ran for five hours in length. Literature on AIDS, and bereavement were given to each participant and assignments were done in preparation for the sessions. The purpose was to train volunteer church members to initiate and conduct AIDS bereavement support groups in their church.

Results

Generally, congruity was observed between the professionals and the six volunteer lay leaders in respect to their reactions during the group sessions to reading material and the presentations given by the professionals. For example, when discussing general bereavement theory, lay leaders demonstrated that they had read the material by coming to the session prepared to discuss what they read, how the reading had stimulated their thoughts about bereavement, and how they might apply what they were learning to their lives in general. Incongruity was observed only in the following situations: (1) Group members spoke more freely and extensively about negative experiences during the one session the minister (co-facilitator) was absent, and (the group itself wanted to expand and explore needs and avenues for advocacy more than the professional leaders did. Participants expressed concerns that African Americans persons with AIDS (PWAs) as well as their families; friends and the communities affected by them are undervalued and shortchanged. Thus, training in bereavement techniques alone may not be enough. They felt there is a need for more programs about AIDS prevention, treatment for those who are ill, and support for those who are grieving.

Participants who had been directly affected by AIDS losses also wanted more material presented on the nature of community and church interactions. Group members recounted their own or others' experiences in seeking help with bereavement needs from established AIDS organizations and from the African American church and community. Their reactions ranged from gratitude and hope to frustration and alienation from established AIDS advocacy groups and their program

efforts. They pointed out that even within the African American community, experiences were mixed, and ranged from isolation and stigmatization to acceptance and warmth.

Table III presents a variety of reactions expressed by participants concerning the way the African American church and community, as well as others in society respond to AIDS sufferers and their families.

Table III
Concerns About Indifference to AIDS

AIDS Advocacy Groups
When AIDS was the gay plague and the Gay Men's Health Crisis was involved, the education got out and the curve fell on the rise of AIDS in the gay community…but when it becomes our problem, where are the same resources?
African American Community
Within our own community, I find that we can talk about a whole lot of things, except when it comes to this illness.
In the 90s, it's a real cultural thing to be 'too blessed' to be bothered with this kind of stuff. We're not going to let them take our joy. I worry about that.
African American Church Community
People feel moralistic, as if they have a right to withhold their expressions of caring and kindness based on the fact that AIDS come from something that no one holds dear…
People express their morals in a manner that says, it's your fault… I need not be concerned, because you brought this on yourself.
Christians say they can't get comfortable with homosexuals.
Neighbors
You can't call on Mary down the block, because she has her own problems and doesn't want to hear about yours. Sometimes, they don't even answer the door.
Family
They don't want to accept the fact that it's here and they have to face it. I have AIDS and my brother-in-law was too scared to come into our house, because he has two children and he doesn't want them to catch it. My sister also had her attitude.
My husband wanted to burn everything in the house.
Pastor
I never told Reverend…I guess he sensed it. He used to always go to see my son. I used to feel so good. It really gave me a high spirit. My own neighbors were too scared to go.

Reactions to specific training topics revealed that participants felt the topics were appropriate and important to include in the training. For example, they responded very strongly to content related to health, emotional needs, and issues involving the African American and the wider communities of AIDS health and support organizations as identified in Table III. Lay leaders' feedback also indicated that they understood most of the ideas and interventions that were presented that would help them in the practical aspects of developing their own support group in the future.

Reviewing transcripts of each session, revealed participants' positive and negative behaviors related to training materials as presented in Tables IV and V.

Table IV
Positive Behaviors Related to Training
1=very low
7=very high

Contributing experiences which parallel topic	7
Making appropriate references to audio / visual material	7
Giving affirmations of topic area	7
Rephrasing or restating topic information	6
Making appropriate references to reading material	5
Asking questions about topic	4

Table V
Negative Behaviors Related to Training
1=very low response
7=very high response

Introducing information not related to one topic	3
Discussing experiences not specific to topic	3
Asking questions not on topic	2
Arriving late	1
Leaving early	1
Missed group session	1
Side talk	1

When asked to evaluate the overall training experience, participants were specific in their recommendations regarding content and process. Their recommendations are listed in Table VI.

Table VI
Evaluation of training

Keep the Same
1. Training topics
2. Reading material
3. Presentation format
Increase
1. Practical training, including "what if situations; hands-on training of role playing
2. Limit setting
3. Advocacy training on many levels
4. Emphasis on creating and maintaining permanent referral materials
5. Connecting with other members and leaders for support and guidance

Spirituality emerged as a very important component of the training. The following statement made by the individual suffering with AIDS speaks to his belief in the power of prayer and the critical role of the minister in helping to heal the mind and spirit, if not the body in the fight against AIDS.

> I was in my bed waiting to undergo a spine operation resulting from AIDS. It was almost 11:00pm on a Monday night. I picked up my bible and started reading, because I remember my mother said, 'just pray.' And who should come in but Reverend…He prayed over me, and told me, 'don't worry, the whole church is behind you. Everything is going to be all right.' I remember waking up because the operation was over. My mother and father were standing there at 4:00 o'clock in the morning. The operation started at 6:30pm. I was in so much pain. I just said, "Dear God let them go home and rest, because I'm going to be all right. Reverend… said, 'I'm going to be alright.' And then once they went home, I had peace…and I've been moving up every since.

From the beginning sessions and throughout the training experience, participants turned to their religious beliefs to make critical group decisions. For example, participants felt that it was important for them to establish a mission statement that would help them make critical decisions in their work together. The mission statement voiced their commitment to spiritual healing as follows:

> Our aim is to focus on healthy community stressing the values of health by caring, sharing, respect and love for everyone involved. Our vision is to recognize and respect the dignity of each person infected and affected by this epidemic and to take community based responsibility dedicated to the achievement of wellness of each and every participant.

Their commitment to spiritual healing provided strength to cope with losses, gave solace and comfort from abandonment and isolating behavior of family and friends, and provided a source of power to take action individually and collectively.

The group was accepting of their need to broaden their knowledge about bereavement dynamics and cultural sensitivity in order to function in their role as group leaders. Extreme sensitivity to the need to give greater importance, status and value to those affected by AIDS in the African American community was stressed. However, they also recognized their limitations. Specifically, they were concerned about the fact that there are only six of them, they have to negotiate the church's rules and culture, and they have no designated funding for the AIDS ministry.

Participants seemed to be especially responsive to the professional level of the group trainers and valued the church and university affiliations. They viewed this

affiliation as one that validated the training experience and the importance of their role as providers of a service to PWAs.

Discussion and Summary

The pilot project described in this paper represents one African American church's response to AIDS suffers. Its emphasis on lay leaders training recognizes the strengths of church leaders to address AIDS bereavement needs within the congregation while identifying the type of help lay leaders need in order to engage in a non-judgmental manner those who grieve AIDS losses. The qualitative analysis of the lay leaders' interactions indicated the training met most of their didactic and emotional needs. Moreover, lay leaders call for churches along with other organizations and institutions of higher learning to build and sustain an infrastructure for support, information and guidance. It points out the general lack of societal support of AIDS ministries and the potential burden lay leaders may experience.

Contrary to popular belief, this group's mission and actions demonstrated that there are those who feel a deep commitment to partner with people with AIDS and those who care for them. The lay leaders' call for the voices of African American PWAs, and those who care for them, to be heard and understood resonates with the pioneering works of Shelton (1998), Moore and Conboy (1998), and Moore and Phillips (1994). These

authors work also parallels Doka's (1989) work on disenfranchised grief. The theme is that partnering can forge beneficial alliances that create new resources.

While this was a very small group, the success of this lay leaders training can be viewed from different perspectives. This approach synthesizes many different theories, interventions and theses. The lay leader-training model may work because it uses the traditional African American church as a vehicle of self-help (Cnaan and Wineburg, 1997). Lay leaders who address their communities' needs lead ministries. In this structure, professionals introduce the intervention and then allow the people affected to exercise optimum control of the content, process and outcomes. Thus, this bereavement model becomes an instrument of change that empowers the participants. The model has transparency in that it allows the African Americans involved to know at all times how things are done and to whom things are done. The intervention stays within the control of the participants who are regarded in the community as insiders. Working in collaboration with the minister and the greater church community, lay-leaders deliver the new message of reconnection and self-healing to a sub-group of the church's mission and ministry – the disenfranchised.

The model is culturally sensitive and appropriate to the unique needs of the specific congregations. Yet the model uses as its foundation an amalgam of multidisciplinary theories, interventions, perspectives, models and literatures: bereavement, AIDS bereavement, group-work, empowerment, ethics informed practices, community organization, organization theory, human development/adult learning theory,

multicultural perspectives and practices. Upon this broad foundation, a distinct and refined intervention was sculpted which can be adapted to other African American church communities and perhaps to other special populations and cultures as well. It has specificity, but it could be universally applied.

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